



# Becoming A Caregiver A Comprehensive Guide for Caregivers

A Joint Project of the Transamerica Center for Health Studies®  
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*Navigate the Future.*

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## Former first lady Rosalynn Carter famously said,

“There are only four kinds of people in the world – those who have been caregivers, those who are caregivers, those who will be caregivers and those who will need caregivers.”

### INTRODUCTION

At some point in most of our lives, most of us will act as a caregiver to a loved one. According to the National Alliance on Caregiving, approximately 34.2 million Americans have provided unpaid care to an adult age 50 or older in the last 12 months. As common as it is, caregiving is largely undiscussed by our society, media, and lawmakers. To better understand caregiving in America, [Transamerica Institute®](#), released [The Many Faces of Caregivers: A Close-Up Look at Caregiving and its Impacts](#), a report on the status of non-professional (or family/friend) caregivers. Transamerica Institute’s survey of over 3,000 non-professional caregivers examined their duties and the impact caregiving has on their lives. It gives demographic portraits of caregivers by employment status, gender, generation, household income, ethnicity, whether they are the primary caregiver, and whether they became a caregiver voluntarily.

The survey found that nine out of 10 non-professional family caregivers feel that it is important to provide a good quality of life for the person they care for, they like helping, and enjoy spending time with their care recipient. However, many caregivers are providing care at their own risk. Fifty-five percent say that their own health is taking a back seat to the health of their care recipient and 69 percent gave little or no consideration to their own financial situation when deciding to become a caregiver. Caregiving can divert time and resources away from employment, raising children, and personal care. The demands on caregivers often result in elevated stress levels and a decline in maintaining personal health. Another set of challenges involve administrative and legal barriers that can occur when helping the care recipient access medical care. In the survey, caregivers were asked what assistance and resources they needed. This guide offers an overview of legal documents, insurance information, financial information as well as resources available to caregivers and care recipients.

### BECOMING A CAREGIVER

Caring for a loved one is a responsibility that affects both the care recipient and the caregiver in several ways. As a caregiver, having legal documents in place that allow you to speak to your care recipients’ doctors, insurance company, and others involved in their care is helpful and often necessary.

### STARTING THE CONVERSATION

According to a survey conducted by AARP, more than 90 percent of people think that it is important to have conversations about end-of-life care with their loved ones, yet fewer than 30 percent have done so. The Transamerica Institute Survey of Caregivers found that only 51 percent of caregivers have a power of attorney or medical proxy in place. And around a quarter of caregivers have discussed legal and medical documents with their care recipient, but have not written them down. One of the goals of this guide is to provide content for the conversation to begin. Caregiver advocates and medical professionals often refer to *the conversation* in which a family discusses the care of a loved one as the first step. Studies suggests that referring to an article, a lecture, or a video on caregiving helps begin *the conversation* by making it part of a normal life event that affects everyone.

Determining that a loved one needs care can be a difficult decision. Sometimes it happens suddenly when an accident or unexpected health event occurs to a loved one (such as a stroke or fall) which results in the need for personal care. But often, there is a more gradual change in health and physical ability and their need for assistance to function day to day. Identifying these early indicators can help facilitate planning for a loved one's care.

(See Care Needs Assessment Tool).

**SIGNS TO LOOK FOR:**

**Emotional Changes**

- Mood swings/changes in emotional state
- Anti-social behavior/isolation
- Abusive behavior/outbursts

**Physical/Cognitive Changes**

- Memory loss/confusion
- Repetition
- Hallucinations
- Loss of muscle function/motor control
- Problems with balance
- Frequent falls
- Difficulties performing routine activities of daily living (e.g., bathing, dressing, walking, eating, etc.)
- Changes in physical appearance (e.g., weight loss, poor hygiene, etc.)
- Difficulty driving

**Home Environment Changes**

- Unusual odors
- Carpet stains or spills
- Pots and pans with burns
- Unopened mail or unpaid bills
- Limited food supply
- Unfilled prescriptions

## Care Needs Assessment Tool

**DIRECTIONS:** Assess your loved one's needs by completing each section of the checklist. If you are unsure of some of the questions, ask your loved one. The purpose of this assessment is to help facilitate a discussion with the care recipient about the type and level of care they need.

Alone	With some help	With much help	Activities of Daily Living (ADLs)
			Can dress and undress?
			Can take a bath or shower?
			Cares about personal hygiene, personal health, and well-being?
			Can go to the bathroom?
			Can eat and prepare meals?
			Can get in and out of bed?
			Can walk, climb stairs, and move around?

Alone	With some help	With much help	Instrumental Activities of Daily Living (ADLs)
			Make and receive phone calls?
			Shop for groceries or personal items?
			Drive or use public transportation?
			Pay bills and manage finances?
			Do laundry?
			Manage household chores (e.g., cleaning house or apartment)?
			Manage medications and general health?

No change	Some change	Major change	Physical Status
			Change in hearing?
			Change in vision, orientation, and perception?
			Change in balance/muscle function/motor control?
			Change in bladder or bowel control?
			Ability to walk?
			Change in health status/condition?
			Change in weight?
			Change in personal hygiene or appearance?

Care Needs Assessment Tool *(continued)*

No change	Some change	Major change	Cognitive Status
			Change in memory?
			Change in decision-making/judgment?
			Maintains a positive attitude?
			Change in emotional state (e.g. mood swings)?
			Interest in socializing and going out?

Yes	No	Sometimes	Home Environment
			Can live alone comfortably and safe?
			Burned pots or pans?
			Broken plates or glasses?
			Unusual odors in floor or carpet?
			Change in home maintenance?
			Change in pet care or plant care?
			Expired/spoiled food in the home?
			Broken appliances?
			Doors and windows secure and locked?
			Furniture accessible and accommodates needs?

## Tips on How to Initiate *the Conversation*

Discussing appropriate long-term care for a loved one can be difficult and uncomfortable for both the care recipient and their family and friends. It can be hard to find the right time to initiate *the conversation* and deciding how to bring up the topic can be stressful.

**Below are a few tips to consider when initiating the conversation:**

### Choosing the right time and place

- Select a location where the care recipient feels comfortable and a time that is most appropriate and not rushed.

### Look for an opening

- Do not initiate the conversation by ordering or patronizing. Avoid acting like a parent by telling them what to do.
- The topic should be incorporated into the conversation gradually and not forced. For example, talking about a news article or segment can raise the topic.

### Listen and respect the care recipient's wishes

- When discussing a long-term care plan, it is important that the care recipient's wishes, consent, and support are accounted for in each step of the process.
  - Understand the priorities of your care recipient (housing, type of care, etc.).
- A primary caregiver can be appointed and the extent of their role should be discussed relative to other caregivers.

### Be prepared to answer questions and concerns

- The care recipient may be concerned or scared and may have numerous questions at the end of *the conversation*. Materials that can help answer their concerns should be made available.
- If possible, share examples or narratives of people's experiences with long-term care as well as pamphlets for different housing options if necessary.
- Give them time to process all the information from *the conversation*.

## PLANNING FOR CARE

### DISCUSSING IMPORTANT LEGAL DOCUMENTS

As mentioned above, caregiving is often not planned, but rather the need arises quickly and unexpectedly from an illness, injury, or from the onset of dementia. Having certain documents in place prior to the need for caregiving can aid the caregiver with the medical and financial aspects of care so they can spend more time on providing comfort and companionship to their loved one.

Granted, discussing these documents is the first challenge. However, knowing the care recipient's wishes regarding where they will live, what type of medical care they will accept or decline, and who they wish to delegate to make medical and financial decisions on their behalf will reduce stress and confusion when the need for care arises. Having some simple legal documents in place before care is needed will allow you to spend time on what is important — spending time with the care recipient. Below is a list of important documents and legal terms that are helpful.

#### Advance Directive

As explained by the American Medical Association, "Advance Directives, whether oral or written, advisory or a formal statutory document, are tools that give patients of all ages and health status the opportunity to express their values, goals for care, and treatment preferences to guide future decisions about health care." Put simply, an Advance Directive is a patient's way of letting medical professionals know what medical interventions they will accept or decline when they are no longer able to speak for themselves. Advance Directives can include instructions on the use of breathing machines, organ donations, dialysis machines, or simply whether or not

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the person wants to be resuscitated when their life is at risk. Sometimes referred to as a living will, an Advanced Directive is limited to end-of-life care when the person is unable to speak for themselves, while a power of attorney or healthcare proxy (see below for explanation) covers overall medical decisions.

Each state has Advance Directive forms through the office of the state's Attorney General or by visiting CaringInfo at: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

### Examples of end-of-life medical decisions when preparing an Advance Directive:

#### Cardiopulmonary Resuscitation (CPR)

- Group of procedures used when a patient has a cardiac/respiratory arrest. Resuscitation procedures include chest compressions, electrical stimulation, medication, or a tube insertion through the mouth or nose that is connected to a mechanical ventilator.

#### Do Not Resuscitate (DNR) and Do Not Attempt to Resuscitate (DNAR) Orders

- According to the American Medical Association, "Orders not to attempt resuscitation (DNAR orders) direct the healthcare team to withhold resuscitative measures in accord with a patient's wishes. DNAR orders can be appropriate for any patient medically at risk of cardiopulmonary arrest, regardless of the patient's age or whether or not the patient is terminally ill. DNAR orders apply in any care setting, in or out of hospital, within the constraints of applicable law."
- DNR can be canceled at any time by informing the physician.

#### Do Not Intubate (DNI) Order

- Similar to the DNR, a DNI order prevents healthcare professionals from performing an intubation which is the placement of a tube in the mouth or nose to support breathing with a mechanical ventilator. Refusing intubation does not mean refusal of other techniques of resuscitation.

#### Artificial Nutrition and Hydration

- Treatment options that help a patient to receive nutrition and hydration when they can no longer receive food and fluids by mouth.

### Power of Attorney

According to the American Bar Association, "a power of attorney gives one or more persons the power to act on your behalf as your agent." Further, "a power of attorney is accepted in all states, but the rules and requirements differ from state to state." A power of attorney can allow an individual to make financial decisions such as signing checks to pay bills, handling tax returns, selling a home, speaking to insurance companies, doctors, and making decisions about medical treatment. Generally speaking, "the power may be limited to a particular activity, such as closing the sale of your home, or be general in its application. The power may give temporary or permanent authority to act on your behalf. The power may take effect immediately, or only upon the occurrence of a future event, usually a determination that you are unable to act for yourself due to mental or physical disability. The latter is called a "springing" power of attorney. A power of attorney may be revoked, but most states require written notice of revocation to the person named to act for you."

### Healthcare Proxy/Healthcare Power of Attorney

Healthcare proxy is essentially a power of attorney for medical decisions. It allows a designated person to make choices about treatments, doctors, and other health-related matters when the care recipient cannot speak for themselves. The level of decision authority is decided by the care recipient; it can range from giving full authority to the designee to make all healthcare-related decisions, or only specified decisions.

## Guardianship

As defined by the American Bar Association, “adult guardianship is the legal means by which a court gives one person or entity the duty and power to make personal and/or property decisions for another, based upon a finding that an adult is not able to make his or her own decisions. A judicial finding of “incapacity” may be based on medical, cognitive, and functional elements, as set out in state law.” Also, “individuals subject to guardianship may be older persons with dementia, adults of any age with intellectual or developmental disabilities, people with mental illness, people with brain injuries or substance abuse – and often individuals with a combination of these conditions.” Once the court appoints the guardian, they “may have authority over a person’s health and personal affairs, financial and property affairs, or both.”

For more information:

<https://www.agingcare.com/articles/how-to-get-guardianship-of-elderly-parents-140693.html>

## HIPAA Privacy Waiver

A helpful form to have in place is a HIPAA (the Health Insurance Portability and Accountability Act – provides data privacy and security safeguards for an individual’s medical information) waiver/release which grants access to a designated individual to discuss the health conditions and information of a loved one with medical professionals and health insurance companies.

HIPAA privacy waiver CaringInfo:

<https://www.caring.com/forms/hipaa-release-form/free-hipaa-release-form.pdf>

## Living Trust

A legal document that allows the primary individual (designee) or a named trustee the power to transfer ownership or title of the primary individual's assets into a trust. While the primary individual still maintains control of those assets throughout their lifetime, the living trust names those who will receive the assets from the primary individual’s trust upon their death.

## Last Will and Testament

Last Will and Testament is a document prepared by an individual that outlines who will receive the assets upon that person's death. An *executor* is also assigned by the individual to implement what is stated in the Will. The *executor* needs to be someone who has no conflict of interest and can be given full, complete confidence to carry out the stated instructions of the deceased (in the Will).

## Living Will

A written declaration which states an individual’s healthcare wishes in terms of their healthcare preferences and end-of-life decisions. It can be very detailed and can include the types of treatment options the individual is willing and unwilling to undergo. It is important to note that a Living Will only outlines the individual’s instructions about their healthcare treatment options, but it does not designate an agent to make those decisions.

## Personal Care Agreement

A formal contract between the care recipient and the caregiver which outlines the care that the caregiver will provide and the compensation that the caregiver will receive for those services. The contract is applicable regardless of whether or not the caregiver is a family member, friend, or healthcare professional. The personal care agreement should be discussed between the care recipient and the caregiver in order to avoid any future conflict. Even if the caregiver will not receive any financial compensation, it is still highly recommended for both care recipient and caregiver to discuss the types of care that will be provided to ensure mutual understanding.

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**Information to include in the personal care agreement includes:**

- Start of care and end date, if known
- Description of services that will be provided by the caregiver
- Number of hours for each service and compensation rate, if applicable
- Location where the services will be provide
- Statement disclosing that the terms of the agreement can be modified

**Other Important Documents**

Additional documents that are important to locate and have organized for both care recipients and caregivers include the following:

- Medical records
- Birth certificate
- Insurance policies including Medicare/Medigap policy information
- Pension or 401(k) statements
- Bank and investment statements
- Social Security benefit/payment information
- Loan agreements
- Stock and Bond certificates and statements
- Mortgage documents
- Tax records and tax-related documents
- Vehicle title(s)

**NAVIGATING HEALTH INSURANCE COVERAGE**

As a caregiver, managing health insurance coverage for a care recipient is an important responsibility. Understanding the different types of health coverage that are available and the different ways of paying for healthcare can empower care recipients to achieve the best value from their health coverage.

Listed below are some of the types of health insurance coverage options that are available:

**MEDICARE**

Medicare is a national health insurance program administered by the Center for Medicare & Medicaid Services (CMS) for individuals age 65 and older. However, individuals under the age of 65 who have End-Stage Renal Disease (ESRD) or amyotrophic lateral sclerosis (ALS/Lou Gehrig’s disease) or receive Social Security Disability Insurance (SSDI) are also eligible for Medicare. Although, Medicare helps to pay for some health expenses, it does not cover long-term care.

**There are two types of Medicare:**

original Medicare (Part A, Part B, and Part D) OR Medicare Advantage (Part C)

Each type and each part include many different plan options. Information about specific Medicare plans can be found at [www.Medicare.gov/find-a-plan](http://www.Medicare.gov/find-a-plan). The online Medicare Plan Finder has comparisons of the costs of different plans, their covered services, their quality ratings, and more.

**Part A (Hospital Insurance)**

Medicare Part A is hospital insurance that provides coverage for inpatient care received through acute care hospitals, long-term care hospitals, inpatient rehabilitation facilities, and mental health care centers among others. Medicare Part A coverage also includes limited home health services, skilled nursing facility care, and hospice care. Medicare Part A is free for those who receive or are eligible to receive Social Security benefits.

## Eligibility for Medicare Part A:

### Qualify for Medicare Part A:

- 65 or older and a U.S. permanent legal resident for at least five consecutive years.
- Receiving, or are eligible for, retirement benefits from Social Security or the Railroad Retirement Board.
- Under 65 and have received Railroad Retirement disability benefits for the prescribed time and you meet the Social Security Act disability requirements.
- Individual or spouse had Medicare-covered government employment.
- Under 65 and have End-Stage Renal Disease (ESRD) or amyotrophic lateral sclerosis (ALS/Lou Gehrig's disease).

### When not eligible for premium-free Medicare Part A, an individual can buy Part A by paying a monthly premium if:

- Age 65 or older, enrolled in Part B, and are either a citizen or a permanent resident who has lived in the United States for five consecutive years immediately before the month in which the individual applies.
- Depending on income and assets, you may pay up to \$411 each month in 2017. The specific amount paid will depend on work history and financial situation.

## Part B (Medial Insurance)

Medicare Part B is medical insurance that provides coverage for outpatient care, preventive services, ambulance services, and medical equipment. Other additional coverage includes part-time or sporadic home health and rehabilitative services. In addition to the eligibility requirements for Medicare Part A mentioned above, an individual may qualify for Medicare Part B if they receive disability benefits or are under the age of 65, but have ESRD or ALS/Lou Gehrig's disease.

Most Part B benefits are subject to yearly deductibles, out-of-pocket copayments, coinsurance, and monthly premiums. Some people who have income or resources higher than a set amount may need to pay higher Part B premiums as determined by the Social Security Administration. Individuals with limited income and resources may be eligible to receive assistance with Part B payments through a variety of programs such as Medicaid.

## Eligibility for Medicare Part B:

### Qualify for Medicare Part B:

- Eligible for premium-free Part A
- Not eligible for premium-free Part A but are 65 years and older and a citizen of the United States or resident or permanent residence and have lived in the United States for five consecutive years before the month during which the individual enrolls in Part B.

## Part D (Prescription Drug Coverage)

Plans administered by private insurance companies but are regulated by the government to provide prescription drug coverage that is not included in Parts A and B. Different Part D plans may have different formularies (lists of which drugs they cover), different premiums (which may be higher if you have a higher income), and different deductibles, copayments, and coinsurance amounts. Some Part D plans require prior authorization before filling certain prescriptions, and may have limits on the quantity of medications received at one time.

Medicare Part D has unusual coverage for prescription drugs, including a gap called the *donut hole*. The 2018 Medicare Part D standard benefit includes a deductible of \$405 (amount that beneficiaries must pay out-of-pocket before their insurance benefits kick in) and a 25 percent co-insurance payment up to the initial coverage maximum of \$3,750 (just for prescription drug costs). Once the total annual drug costs exceed \$3,750, patients reach the coverage gap (the donut hole). During the coverage gap stage, after \$3,750 in prescription drug costs, beneficiaries pay a larger percentage until their total out-of-pocket spending reaches \$5,000. At \$5,000 of out-of-pocket prescription drug spending, beneficiaries reach catastrophic coverage, where they pay either 5 percent of total drug cost or \$3.35 for generics and \$8.35 for brand-name drugs.

More about the different parts of Medicare on our Medicare Guide:

<https://www.transamericacenterforhealthstudies.org/affordable-care-act/medicare-guide>

## Part C (Medicare Advantage)

Separate from original Medicare (Parts A, B, and D), Medicare Advantage/Part C plans are private insurance plans that provide coverage for hospital, medical, and prescription drugs. Every Medicare Advantage/Part C plan covers all of the benefits of Original Medicare except for hospice care and some care in clinical research studies.

Many Medicare Advantage/Part C plans offer vision, hearing, and dental services. Medicare Advantage/Part C plans may have monthly premiums in addition to the Part B premium, but have yearly limits on the amount that is required out-of-pocket. Different Medicare Advantage/Part C plans may have different deductibles, copayments, and coinsurance policies to compare prior to choosing a plan. They also have different requirements on which doctors and which facilities are covered. Registration for Medicare Advantage/Part C is available during an individual's initial enrollment period or during annual enrollment periods.

## Medicare Open Enrollment

Individuals are first eligible to enroll in Medicare during the seven months around their 65th birthday (three months before, the month of, and three months after). For example, a person turning 65 in July is eligible to enroll in Medicare from April through October of that year. Those who do not enroll in Medicare by the end of the third month after their 65th birthday are subject to a lifetime penalty and higher monthly fees after enrollment. For instance, if someone misses the initial enrollment period for Part B, he or she faces an additional monthly premium of 10 percent for every full 12 months he or she was eligible but did not enroll, for life. Registration for Medicare Advantage/Part C is available during initial enrollment period or during annual open enrollment periods without penalty.

Individuals already enrolled in Medicare can make changes to their plan during the annual open enrollment period that takes place November 1st through December 15th. Health plans and benefits (including costs) change every year, so it is important for everyone to consider their current healthcare plan during open enrollment and make any necessary changes to their coverage.

To apply for Medicare visit the Social Security Administration: [www.ssa.gov](http://www.ssa.gov)

## **MEDIGAP**

Medigap is supplemental insurance sold by private companies that covers services that are not covered by Medicare Parts A, B, and D (original Medicare) such as copayments, coinsurance, deductibles, and other services or supplies. However, Medigap plans are not necessary for those covered under Medicare Part C (Medicare Advantage).

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## MEDIGAP *(continued)*

The Medigap initial enrollment period is different from the Medicare initial enrollment period, taking place slightly later and once an individual is enrolled in Medicare – the six-month period that begins on the first day of the month in which they turn 65 and are enrolled in Part B. If not enrolled in Part B when they first turn 65, then their Medigap open enrollment period does not begin until they obtain Part B. If an individual waits to enroll in Medigap until after their six-month Medigap open enrollment period is over, they may have limited Medigap options and may be required to pay higher fees.

If an individual is enrolled in a Medicare Advantage plan, it is illegal for anyone to enroll them in a Medigap policy unless they are switching back to original Medicare. However, if an individual has a Medigap plan, they may join a Medicare Advantage plan, but they cannot use a Medigap plan to pay for Medicare Advantage copayments, deductibles, or premiums as they might for an original Medicare plan.

## MEDICAID

Medicaid is a joint federal and state program that provides health coverage to low income adults, children, pregnant women, elderly adults and individuals with disabilities.

Medicaid can provide supplemental coverage to Medicare recipients, known as *dual-eligible* individuals, who qualify for both Medicare and Medicaid based on their income. Medicaid benefits for dual-eligible individuals include coverage of full or partial co-payments, co-insurance and deductibles.

### Medicaid and Long-Term Care

Generally speaking, Medicaid covers long-term care only if an individual meets the following eligibility criteria:

Financial Criteria	Functional Criteria	General Criteria
<p>Proof of financial need to cover long-term care expenses</p> <ul style="list-style-type: none"><li>Limited assets and income – assets that are exempt in the evaluation include a primary residence, personal belongings, one motor vehicle, property necessary to self-support, and life insurance under \$1,500.</li></ul>	<p>Need for long-term care services based on an evaluation conducted by a medical specialist</p> <ul style="list-style-type: none"><li>Assessment evaluates whether an individual can perform the daily living activities and determines whether an individual qualifies for nursing home care, assisted living, or home and community-based services.</li></ul>	<ul style="list-style-type: none"><li>Age 65 or older or permanently disabled or blind</li><li>A U.S. citizen or permanent resident</li><li>Resident of the state where they apply</li></ul>

To apply for Medicaid, contact the state Medicaid (may be called something different than ‘Medicaid’ in different states) assistance office.

## THE VETERANS ADMINISTRATION

In addition to Medicare and Medicaid, veterans and their families have additional health insurance options available to them. The Veterans Administration (VA) provides exclusive healthcare services for veterans in VA medical facilities. VA benefits may be received in conjunction with other health insurance or as stand-alone coverage. Enrollment in VA is optional and can be terminated or reinstated. It is generally available to veterans of any age who were honorably discharged from active military service after at least two years, and reserve members who completed the full period for which they were called or ordered to active duty. Costs vary depending on years of service, income, and the nature of the care. All service-related care is free within the VA system.

Another health insurance option available for military service members is *TRICARE*, which is provided by the Department of Defense for active duty personnel military retirees (those who completed 20 years of service), and their dependents. It may also be used in conjunction with other health insurance or as stand-alone coverage. To enroll, veterans must also be registered in the Defense Enrollment Eligibility Reporting System (DEERS). Veterans may enroll in Medicare or Medicaid while receiving VA or TRICARE, but cooperation between the programs varies.

## Veterans and Long-Term Care

To qualify for long-term care benefits from the VA, a Veteran must meet the following criteria:

- Have a service-related disability of 70 percent or higher.
- Be unemployable and have a 60 percent service-related disability or be permanently disabled.
- Have a disability that occurred during active duty that requires nursing home care.
- Have a disability that was not caused during active duty but requires nursing home care and meets the income and asset criteria
- Case-by-case basis for veterans who need post-acute rehabilitation, hospice etc.

Long-term care benefits that are available to veterans include VA-owned nursing homes, contracted private nursing homes, and community living centers that are operated by the VA. To be eligible for VA nursing homes, veterans must demonstrate physical and/or mental impairment that requires home level care.

Community living centers are designed for short-term care such as rehabilitation or end-of-life care for up to 100 days. The VA also offers long-term community care to veterans who do not qualify for nursing homes or prefer to live at home but still require nonmedical assistance. However, veterans may be subject to copayments for some services, which depend on the veterans' health system priority group, type of care or services provided, and their financial circumstances.

**More about healthcare for veterans:**

<https://www.va.gov/geriatrics/Guide/LongTermCare/>

**Or visit our Veterans Healthcare Guide:**

<https://www.transamericacenterforhealthstudies.org/affordable-care-act/veterans>

## Veterans-Directed Home and Community-Based Services (VD-HCBS)

The VD-HCBS program serves veterans of all ages enrolled in VA healthcare who are at risk for institutional placement. The program provides home and community-based services to allow veterans to live independently in their own home. "The determination of whether a Veteran is "in need of nursing home care" is made by the VA Medical Centers based upon a predefined set of functional criteria and social indicators." Beneficiaries can select the goods and services that meet their needs and manage their budget on personal care services, which can include paying family and friends to serve as a caregiver.

**More information on the VD-HCBS program:** <https://www.acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based>

## OTHER GOVERNMENT PROGRAMS

There are several governmental programs that provide resources for senior citizens and their caregivers. However, these programs sometimes vary by state. The types of resources that are available range from home health aides, nursing care, meal delivery, transportation, counseling, and legal aid to name a few. Some states offer caregiver assistance programs, which provide counseling and information for caregivers.

**Below are some of the types of programs that are available:**

### Program of All-Inclusive Care for the Elderly (PACE)

Available in 28 states, PACE offers integrated Medicaid and Medicare benefits, as well as medical, social and long-term care services for the elderly. Some of the services that PACE covers include primary care, emergency services, home care, meals, and therapy. To join PACE, an individual must be enrolled in either Medicare or Medicaid, be 55 years or older, live in one of the eligible 28 states, need nursing home-level care, and be able to live safely in the community with help from PACE.

For more information about PACE:

<https://www.medicare.gov/find-a-plan/questions/pace-home.aspx>

## Administration on Aging (AoA)

A federal government agency that provides services and programs available to help the elderly live independently in their homes. Some of the programs that AoA offers include legal assistance, long-term care, elderly abuse prevention, fall prevention, and respite care.

To learn more visit: <https://www.acl.gov/about-acl/administration-aging>

## State Agencies for Aging

State service provides a list of state aging assistance programs with their eligibility requirements and application process.

To look at the assistance programs available by state:  
<https://www.eldercaredirectory.org/state-resources.htm>

## Area Agencies on Aging

Regional service provides assistance to find programs to support the elderly that are available locally. Counselors are also available to help individuals with the application process.

To contact a local Area Agency on Aging:  
<https://www.agingcare.com/local/Area-Agency-on-Aging>

## PRIVATE INSURANCE

Private long-term care insurance plans are available to offset out-of-pocket costs to pay for home assistance, nursing home, or assisted living facilities. However, these private insurance plans range in cost, the higher the coverage, the higher the cost. Some employers offer retirement plans that include optional long-term care coverage. When deciding to enroll in a private long-term care insurance plan, it is important to examine what services or care the plan covers and the percent of costs that it covers.

## FINANCIAL SUPPORT FOR CAREGIVERS

Caring for a loved one can impact a caregiver's personal finances and their ability to save for their financial future. The level of financial impact that caregivers face varies according to their financial circumstances, length of caregiving, and the care recipients' financial savings and medical coverage. Although government programs such as Medicare, Medicaid, and Social Security have helped with the cost of medical care for the elderly, there still remains a large out-of-pocket cost for the care recipient, their family, and/or the caregiver. Understanding the types of resources or programs that are available to help offset the financial cost of caregiving can help reduce the stress and anxiety for all involved.

**Listed below are some financial support options for caregivers:**

### FAMILY AND MEDICAL LEAVE ACT (FMLA)

FMLA is a law requiring employers to allow employees to take *unpaid* job-protected leave (up to 12 weeks) under certain circumstances.

*(continued on page 15)*

## The FMLA entitles eligible employees to a 12-week leave in a 12-month period for the following reasons:

- A serious health condition that prevents the employee from performing their essential job functions.
- The birth of a child or the placement of a child with the employee for adoption or foster care.
- Caring for a sick family member (spouse, child, or parent) with a serious condition.
- When a spouse, son, daughter, or parent is a military member on covered active duty or called to covered active duty status resulting in a serious injury.
  - Caring for a service member with a serious injury or illness, which includes a spouse, child, or parent, may take a leave of up to 26 work weeks during a single 12-month period.

Those working for a small employer or recently hired may not qualify for a protected leave. FMLA only applies to employers who meet the following criteria:

- A private sector employer with 50 or more employees.
- Public employers which include local, state, or federal government agencies regardless of the number of employees
- Private or public elementary or secondary schools regardless of the number of employees

Likewise, employees are eligible to take FMLA leave if they:

- Work for an employer who meets the FMLA criteria.
- The employee has worked for the employer for at least 12 months (or at least for 1,250 hours within 12 months).
- Works at a location where the employer has at least 50 employees within 75 miles.

## Government Programs

An unpaid caregiver for a family member or friend may have difficulty managing their own finances. This is especially true if they have to reduce their number of work hours, or have to quit their job to become a full-time caregiver. But there are ways to receive some compensation for caregiving duties.

### Cash for Counseling Program

Available for Medicaid recipients who are eligible for in-home care benefits, this program gives a direct payment to spend on their own care. Care recipients can decide whether to use their payments to pay a family member or friend to serve as a caregiver, or use the money to make their home more safe and comfortable.

Currently, the program is only offered in a few states: Alabama, Arkansas, Florida, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Jersey, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia. Some states have similar programs through Medicaid but use a different name. The amount of payment that the recipient receives depends on a Medicaid assessment of need and the pay rate of in-home care aides, in that particular state. Even if the person receiving care does not qualify for Medicaid, they may still qualify for other state based in-home care programs.

Eligibility for Cash for Counseling Program (may vary by state):

- Proof of financial need
  - Proof of Medicaid coverage or other government cash assistance program.
- Proof of in-home care need
  - Assessment must show an in-home care need

*(continued on page 16)*

## Payment:

- Based on the assessment, the program will determine how many monthly hours of in-home care assistance is needed.
- The program uses both the rate of pay of in-home care workers and the projected hours of care needed to determine the total monthly for the care recipient.
- The care recipient decides who to appoint as the primary caregiver and how much the primary caregiver will be paid from the program's monthly payment. The caregiver must be paid at least the state minimum wage.

To learn whether a state offers cash assistance programs, contact your local Medicaid, human services, or social services office, or local [Area Agency on Aging](#) for assistance.

## Becoming a Certified In-Home Care Aide

If the program or insurance policy for the care recipient mandates only state-certified in-home care aides, the caregiver has the option to become certified.

- The [National Family Caregivers Association](#) or [Family Caregiver Alliance](#) have information about how to become a certified in-home care aide.
- Local adult schools or community colleges may offer certification classes at a low cost.

The list of caregiving training requirements by state:

<https://www.caregiverlist.com/Caregiver-Training-Requirements-By-State.aspx>

Once the caregiver has become certified, draft a personal care agreement that outlines the services that will be provided by the caregiver and the payment that the caregiver will receive for those services. To learn more about personal care agreements, see the legal section of this guide.

## Dependent Tax Exemptions

If the direct pay options described above do not apply, a caregiver may be eligible to claim the care recipient as a dependent on their income tax return if they meet the following criteria:

### Preliminary Criteria

- The caregiver cannot be claimed as a dependent by another taxpayer.
- The dependent (care recipient) must be a citizen or permanent resident of the U.S.
- The dependent (care recipient) cannot file a joint tax return with a spouse.

### Secondary Criteria

- The dependent must be a relative of the caregiver but does not have to live with the caregiver.  
Ex: Mother, father, grandparent, step-parent, mother-in-law, and father-in-law.
- The care recipient's gross income for the tax year must be less than \$4,050 (excluding social security).
- The caregiver must cover more than 50 percent of the care recipient's living expenses including food, housing, medical expenses, transportation etc.
  - Mortgage, utilities, and household cost are also included, if the care recipient lives with the caregiver.

Additionally, medical expenses for the care recipient can be included in the caregiver's itemized deductibles.

If more than one person serves as a caregiver for at least 10 percent of the care recipient's care an [IRS Form 2120: Multiple-Support Declaration](#) can be filed.

For more information on how to file a care recipient as a dependent, see [IRS Publication 501: Exemptions, Standard Deductions and Filing Information](#).

## Veterans Improved Pensions

Financial assistance to veterans with financial need who are 65 years or older, and have been in service for at least 90 days. Veterans who are totally or permanently disabled, receiving nursing care, Social Security disability insurance, or supplemental security income are also eligible.

There are three tiers of assistance:

### Level 1 – Basic Pension

Veterans with the lowest income

- Must have an income less than \$12,907 a year or less than \$16,902 a year (with a spouse or dependent).

### Level 2 – Housebound Pension

Veterans who wish to remain in their home but need regular assistance, as determined by a physician.

- Care can be provided by a family member or caregiver agency. Family members would be paid for their services.
  - To be eligible, a veteran must have an income of less than \$15,773 a year or less than \$19,770 a year with a spouse or dependent.

### Level 3 – Aid and Attendance Pension

Veterans who require assistance for activities of daily living such as bathing, eating, or dressing.

- To be eligible, a veteran must have an income of less than \$21,531 a year or less than \$25,525 with a spouse or dependent.

For more information on veteran pension requirements for long-term care or home care:

<https://www.agingcare.com/articles/vets-financial-aid-long-term-care-home-health-care-138105.htm>

## Supplemental Security Income (SSI)

Monthly cash benefit provided from the federal government to meet the basic needs (e.g. food, clothing, and shelter) for low income older adults and individuals with disabilities.

### To be eligible the care recipient must be:

- 65 or older, or blind or disabled
- U.S. citizen or permanent resident who resides in one of the 50 states, the District of Columbia, or the Northern Mariana Islands
- Financial resources (cash, bank accounts, stocks and bonds) cannot exceed \$2,000 per person or \$3,000 per couple

More information on eligibility and how to apply: <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>

## CARING FOR THE CAREGIVER

Serving as a caregiver can be both rewarding and stressful. Balancing caregiving duties, family, and personal wellbeing can lead to burnout. If the caregiver's physical, mental, and emotional health are not well, it can affect their ability to provide care, and as a result, can affect the care recipient's health and wellbeing. Caregivers need to learn how to take care of themselves as a caregiver and not let their role as a caregiver define them, which can be the first step to a healthy lifestyle. This section will discuss strategies for managing stress, seeking support services, and recognizing burnout.

### RECOGNIZING CAREGIVING BURNOUT

Often, caregivers prioritize the health and wellbeing of their care recipient over their own health. They neglect their symptoms of exhaustion in order to care for their loved one, which can increase their risk for depression, chronic illness, and affect their quality of life. To prevent these risks early on, it is important to recognize symptoms of both physical, emotional, and mental burnout.

Listed below are some common symptoms of burnout among caregivers:

Physical Health	Emotional/Mental Health
<ul style="list-style-type: none"> <li>• Sleep deprivation or changes in sleep pattern</li> <li>• Constantly being tired/exhausted (no energy)</li> <li>• Poor eating habits/changes in weight</li> <li>• Getting sick easily</li> <li>• New or worsening health problems</li> <li>• Headaches</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of interest in activities that were previously enjoyed</li> <li>• Changes in mood</li> <li>• Emotional exhaustion</li> <li>• Excessive use of alcohol, sleep medication</li> <li>• Easily irritated/aggressive behavior</li> <li>• Resentful towards the care recipient</li> <li>• Have trouble concentrating</li> <li>• Feel little satisfaction in quality of life</li> <li>• Spend less time caring for their wellbeing</li> <li>• Depression</li> </ul>

Recognizing symptoms of burnout can serve as an important indicator in a caregiver's life. The next section of this guide will highlight how to prevent burnout and how caregivers can care for their own health while being caregivers.

## CARING FOR THE CAREGIVER'S HEALTH

As mentioned above, the caregiver's health is equally important to that of the care recipient. Stress management practices can prevent high levels of stress and anxiety among caregivers.

Below are some strategies and practices for caregivers to minimize caregiver stress:

### 1 Make caregiving a team effort

Caring for a loved one is a team effort and not a one-person role. Asking for help does not make someone a bad caregiver. On the contrary, having family members and friends help with caregiving responsibilities, which can range from checking up on the care recipient to managing their medication, can minimize the primary caregiver's stress. Every contribution can have a tremendous impact on reducing the stress of the primary caregiver.

### 2 Make medical professionals part of the care team

Adding medical professionals to the care team is valuable because they can provide useful tips and resources to help facilitate a caregiver's responsibilities and duties. They can also refer the caregiver to support groups.

### 3 Take breaks while caregiving

Taking a 15 to 20 minute break throughout the day to relax, can go a long way for emotional and mental health. This can simply be doing something that is fun and relaxing during breaks.

### 4 Sleep, exercise, and eat healthy

The caregiver's physical health is as important as that of the care recipient. Exercising at least once a day is a good method for reducing stress. It can be as simple as a 20 minute walk, a short run, or a yoga class. Sleeping well, eating well, and exercising can give the caregiver the energy to tackle daily caregiving responsibilities.

### 5 Care and monitor the caregiver's health

The caregiver should see their doctor regularly for checkups to maintain optimal health. If caregiving has taken a toll on their health, they can discuss those changes with their primary care provider.

### 6 Attend support groups for caregivers

Knowing that others are going through the same experience can be comforting. Speaking with other caregivers about their experiences can affirm the challenges and benefits of becoming a caregiver. It can also provide information on strategies and resources to help with caregiving.

Services and support groups that are available in the community:

<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

## SUPPORT SERVICES AND RESOURCES FOR THE CAREGIVER

### Administration on Community Living (ACL)

**Website:** [www.acl.gov](http://www.acl.gov)

**Description:** Federal agency responsible for addressing the concerns of the elderly and their caregivers.

**Key Resources:**

- National Family Caregiver Support Program – provides resources, counseling, and training to help support caregivers
- Health and Wellness Program – addresses chronic disease management, injury prevention, and provides home delivery meal service for older adults

### American Bar Association

**Website:** [www.americanbar.org](http://www.americanbar.org)

**Description:** A voluntary professional organization dedicated to serving attorneys, improving the legal profession, and eliminating bias and enhancing diversity.

**Key Resources:**

- Definition of health-related legal terms
- Information on healthcare laws

### Alzheimer's Association

**Website:** [www.Alz.org](http://www.Alz.org)

**Description:** Provides support and resources for individuals with Alzheimer's and other dementia.

**Key Resources:**

- [Alzheimer's Navigator](#) – An assessment tool that helps those facing dementia and Alzheimer's, to determine their needs
- [Community Resource Finder](#) – database of programs, services, housing and care services, and legal aid
- 2017 Caregiver's Guide: <http://ow.ly/3IBO30espPs>

### Benefits Checkup

**Website:** [www.benefitscheckup.org](http://www.benefitscheckup.org)

**Description:** Online tool provided by the National Council on Aging to help individuals over the age of 55 identify benefits.

**Key Resources:**

- Search benefits program by category (e.g. medication, healthcare, housing, etc.)
- Supplemental Nutrition Assistance Program (SNAP) map  
[www.benefitscheckup.org/resources/snap/](http://www.benefitscheckup.org/resources/snap/)

### AARP

**Website:** [www.aarp.org/caregiving](http://www.aarp.org/caregiving)

**Description:** Provides a range of resources, tools, guides, and helpful forms for caregiving.

**Key Resources:**

- AARP Care Guides: [www.aarp.org/careguides](http://www.aarp.org/careguides)
- AARP Caregiving Tools-help find services  
[www.aarp.org/caregivingtools](http://www.aarp.org/caregivingtools)
- Online Caregiving Community-connect with other caregivers

### Caregiver Action Network

**Website:** [www.caregiveraction.org](http://www.caregiveraction.org)

**Description:** Nonprofit provides education, peer support, and resources to caregivers.

**Key Resources:**

- Family Caregiver Toolbox – includes tips, videos, and FAQs
- Care Community-discussion forums

### Caring.com

**Website:** [www.caring.com](http://www.caring.com)

**Description:** Provides caregivers with support and resources.

**Key Resources:**

- Online tool to help find senior living
- Information on housing options and assisted living
- Online support groups and tips for caregivers

### Center for Medicare and Medicaid Services

**Website:** [www.medicare.gov](http://www.medicare.gov)

**Description:** Federal health insurance programs for seniors, persons with a disability, or low-income individuals, including children and pregnant women

**Key Resources:**

- Information on Medicare and Medicaid
- Online tools to compare home healthcare agencies and nursing homes

## SUPPORT SERVICES AND RESOURCES FOR THE CAREGIVER *(continued)*

<p><b>Caring from a Distance</b></p> <p><b>Website:</b> <a href="http://www.cfad.org">www.cfad.org</a></p> <p><b>Description:</b> Provides help for long-distance caregivers by offering a selection of online tools to help coordinate a caregiving plan.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Articles and links to caregiver support programs</li> </ul>	<p><b>Consumer Financial Protection Bureau (CFPB)</b></p> <p><b>Website:</b> <a href="http://www.consumerfinance.gov">www.consumerfinance.gov</a></p> <p><b>Description:</b> Helps consumers get necessary information to make sound financial decisions.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Resources available to help individuals who are 65 and older</li> <li>• Tips on how to avoid mail fraud</li> <li>• Resources for caregivers on how to manage someone else's money</li> </ul>
<p><b>CaringInfo</b></p> <p><b>Website:</b> <a href="http://www.caringinfo.org">www.caringinfo.org</a></p> <p><b>Description:</b> Program of the National Hospice and Palliative Care Organization that provides resources to help individuals make decisions about end-of-life care.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Links to important forms (e.g. Advance Directives)</li> <li>• Guides for caregiving and end-of-life care</li> <li>• Bilingual resources (Spanish, Mandarin, etc.)</li> </ul>	<p><b>Consumer Voice</b></p> <p><b>Website:</b> <a href="http://www.theconsumervoic.org">www.theconsumervoic.org</a></p> <p><b>Description:</b> Consumer support on issues related to long-term care.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Consumer guides on long-term care</li> <li>• Resources on nursing and assisted living</li> <li>• Policy updates on long-term care</li> </ul>
<p><b>Eldercare Locator</b></p> <p><b>Website:</b> <a href="http://www.eldercare.gov">www.eldercare.gov</a></p> <p><b>Description:</b> Sponsored by the Administration on Aging to help individuals find local caregiving services and resources.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Online tool to help find a range of programs available in local areas</li> <li>• Fact sheets, publications and links to information pertaining to long-term care planning and checking benefits</li> </ul>	<p><b>Lotsa Helping Hands</b></p> <p><b>Website:</b> <a href="http://www.lotsahelpinghands.com">www.lotsahelpinghands.com</a></p> <p><b>Description:</b> Platform that brings together caregivers and volunteers through online communities.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Help Calendar – helps organize rides to medical appointments and meals</li> </ul>
<p><b>Elizabeth Dole Foundation</b></p> <p><b>Website:</b> <a href="http://www.elizabethdolefoundation.org">www.elizabethdolefoundation.org</a></p> <p><b>Description:</b> Helps and empowers military caregivers and their families.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Hidden Heroes Caregiver Community – online support group for military caregivers</li> <li>• Guides and studies</li> </ul>	<p><b>Milken Institute Center for the Future of Aging</b></p> <p><b>Website:</b> <a href="http://aging.milkeninstitute.org/">http://aging.milkeninstitute.org/</a></p> <p><b>Description:</b> Promotes healthy, productive and purposeful aging.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Publications and articles on center research and affiliated organizations.</li> <li>• Quarterly publications focusing on various topics related to aging</li> </ul>

## SUPPORT SERVICES AND RESOURCES FOR THE CAREGIVER *(continued)*

<p><b>Family Caregiver Alliance</b></p> <p><b>Website:</b> <a href="http://www.caregiver.org">www.caregiver.org</a></p> <p><b>Description:</b> Community-based nonprofit that addresses the needs of caregivers providing long-term care.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Family Care Navigator — helps caregivers locate support services by state</li> <li>• FCA CareJourney — Online information, support, and resources for family caregivers</li> <li>• National Center on Caregiving—fact sheets and publications on policy changes</li> </ul>	<p><b>National Academy of Elder Law Attorney</b></p> <p><b>Website:</b> <a href="http://www.naela.org">www.naela.org</a></p> <p><b>Description:</b> Association of attorneys who specialize in legal services for older adults and individuals with special needs.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Weekly updates on legislation changes</li> <li>• Newsletters on special needs issues and topics concerning older adults</li> <li>• List NAELA lawyers by practice area</li> </ul>
<p><b>National Alliance for Caregiving</b></p> <p><b>Website:</b> <a href="http://www.caregiving.org">www.caregiving.org</a></p> <p><b>Description:</b> Assists the caregiver and the care recipient through research, advocacy and innovation.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Family caregiving policy updates</li> <li>• Links to resources for caregivers (including guides)</li> </ul>	<p><b>National Association for Home Care and Hospice</b></p> <p><b>Website:</b> <a href="http://www.nahc.org">www.nahc.org</a></p> <p><b>Description:</b> Information for consumers about how to select a home care provider or hospice agency.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Home Care and Hospice Agency locator-online database of home care and hospice agencies: <a href="https://agencylocator.nahc.org">https://agencylocator.nahc.org</a></li> </ul>
<p><b>National Association of States United for Aging and Disability (NASUAD)</b></p> <p><b>Website:</b> <a href="http://www.nasuad.org">www.nasuad.org</a></p> <p><b>Description:</b> Represents state agencies on aging and disabilities. Provides support for caregivers and people who are older and have a disability.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Information on medical coverage, consumer reports, and programs</li> </ul>	<p><b>National Center on Elder Abuse</b></p> <p><b>Website:</b> <a href="http://www.ncea.acl.gov">www.ncea.acl.gov</a></p> <p><b>Description:</b> National resource center dedicated to the prevention of elder mistreatment.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• State resources (e.g. laws and regulations)</li> <li>• Information on elder rights</li> <li>• Publications on the prevention of elder abuse</li> </ul>
<p><b>National Association of Area Agencies on Aging</b></p> <p><b>Website:</b> <a href="http://www.n4a.org">www.n4a.org</a></p> <p><b>Description:</b> Nationwide network of agencies with local resources available for older adults and information on caregiving.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Guides on home improvement scams, benefits for seniors, and eldercare locator, etc.</li> <li>• Publications/articles on being a caregiver</li> </ul>	<p><b>National Clearinghouse for Long-Term Care Information</b></p> <p><b>Website:</b> <a href="http://www.longtermcare.gov">www.longtermcare.gov</a></p> <p><b>Description:</b> Information and tools to help plan for long-term care needs.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Planning Ahead for Long-Term Care factsheet.</li> <li>• Resources for people already receiving long-term care</li> </ul>

## SUPPORT SERVICES AND RESOURCES FOR THE CAREGIVER *(continued)*

<p><b>National Council on Aging</b></p> <p><b>Website:</b> <a href="http://www.ncoa.org">www.ncoa.org</a></p> <p><b>Description:</b> Community programs and services, online help, and advocacy.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Chronic disease management resources and information</li> <li>• Flu+You – Campaign dedicated to educating older adults about the flu</li> </ul>	<p><b>National Respite Network</b></p> <p><b>Website:</b> <a href="http://www.archrespite.org">www.archrespite.org</a></p> <p><b>Description:</b> Helps locate respite services.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Information on respite funding and caregiver support</li> <li>• Consumer guide for family caregivers about respite services</li> </ul>
<p><b>National Hospice and Palliative Care Organization</b></p> <p><b>Website:</b> <a href="http://www.nhpco.org">www.nhpco.org</a></p> <p><b>Description:</b> Provides consumers with information on hospice care and hospice programs.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Tools to assess and monitor the quality of care and services provided by hospice agencies</li> <li>• Information on advance care planning</li> </ul>	<p><b>Next Step in Caregiving</b></p> <p><b>Website:</b> <a href="http://nextstepincare.org">nextstepincare.org</a></p> <p><b>Description:</b> Helps caregivers, care recipients, and healthcare providers with the transition to and from hospitals, nursing homes, in-home care and rehab.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Guides and checklist on caregiving, hospital stay and discharge planning, and preparing for rehabilitation and home care</li> </ul>
<p><b>National Institute on Aging</b></p> <p><b>Website:</b> <a href="http://www.nia.nih.gov/health/caregiving">www.nia.nih.gov/health/caregiving</a></p> <p><b>Description:</b> Primary federal agency supporting and conducting research on aging and Alzheimer’s disease.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Information for caregivers on advanced care planning and long-distance caregiving</li> <li>• Learn how to care for a person with Alzheimer’s or dementia</li> </ul>	<p><b>Seniors Farmers’ Market Nutrition Program (SFMNP)</b></p> <p><b>Website:</b> <a href="http://www.fns.usda.gov/sfmnp">www.fns.usda.gov/sfmnp</a></p> <p><b>Description:</b> Program that offers affordable healthy foods to low-income seniors.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Provides low-income seniors with coupons for eligible foods at farmers’ markets and community agriculture programs</li> </ul>
<p><b>State Health Insurance Assistance Program</b></p> <p><b>Website:</b> <a href="http://www.shiptacenter.org">www.shiptacenter.org</a></p> <p><b>Description:</b> Free one-on-one insurance counseling and assistance for Medicare beneficiaries, their family and caregiver.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Locate state-specific SHIP organization for counseling and assistance</li> </ul>	<p><b>Veterans Affairs</b></p> <p><b>Website:</b> <a href="https://www.caregiver.va.gov/">https://www.caregiver.va.gov/</a></p> <p><b>Description:</b> Support and services for families caring for veterans.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Connects caregivers with support programs</li> <li>• Resources on home care and healthcare centers</li> </ul>

## SUPPORT SERVICES AND RESOURCES FOR THE CAREGIVER (continued)

### Social Security Administration

**Website:** [www.ssa.gov](http://www.ssa.gov)

**Description:** Federal government retirement, disability, and survivor benefits program.

**Key Resources:**

- Access statements online
- Beneficiary information

### Well Spouse Association

**Website:** <http://www.wellspouse.org/>

**Description:** Peer support and education for caregiving spouses.

**Key Resources:**

- Local support groups
- Resources for caregivers regarding end-of-life care, disability, government benefits etc.

### The Conversation Project

**Website:** <http://theconversationproject.org/>

**Description:** Helps people talk about their wishes for end-of-life care.

**Key Resources:**

- Guides on starting end-of-life care conversations (in several languages)
- Information on choosing a healthcare proxy and talking to doctors about end-of-life care

### Women's Institute for a Secure Retirement (WISER)

**Website:** [www.wiserwomen.org/](http://www.wiserwomen.org/)

**Description:** Information, tools, and resources to improve the long-term financial security of women.

**Key Resources:**

- National Resource Center on Women and Retirement Planning—assists women in planning for their financial future, health, and long-term care needs

### SCAN Foundation

**Website:** <http://www.thescanfoundation.org/>

**Description:** Focuses on health and supportive services for independent seniors

**Key Resources:**

- Publications about improving high-quality services for older adults

## FREE AND DISCOUNTED SUPPORT SERVICES FOR CARE RECIPIENTS

<p><b>Adult Day Care Centers</b></p> <p><b>Website:</b> <a href="http://www.agingcare.com/local/adult-day-care">www.agingcare.com/local/adult-day-care</a></p> <p><b>Description:</b> Daily social engagement and health-related services in a supervised setting, including meals and transportation.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Search local adult day care centers and find information on the 3 types of adult day care</li> <li>• Social Adult Day Care, Adult Day Healthcare, Alzheimer’s and Dementia Day Care</li> </ul>	<p><b>State Pharmaceutical Assistance Programs (SPAPS)</b></p> <p><b>Website:</b> <a href="http://www.medicareinteractive.org/pdf/SPAP-Chart.pdf">www.medicareinteractive.org/pdf/SPAP-Chart.pdf</a></p> <p><b>Description:</b> Some states offer programs to help with prescription drug costs for residents with chronic illnesses.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Direct website links and phone numbers to the specific states with SPAPs</li> </ul>
<p><b>Partnership for Prescription Assistance</b></p> <p><b>Website:</b> <a href="http://www.pparx.org/gethelp">www.pparx.org/gethelp</a></p> <p><b>Description:</b> Free online service enabling users to search their prescriptions and find eligible payment assistance programs.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Search prescription medicines, input basic coverage and apply directly to eligible assistance programs</li> </ul>	<p><b>Lifeline</b></p> <p><b>Website:</b> <a href="http://www.lifelinesupport.org/ls/">www.lifelinesupport.org/ls/</a></p> <p><b>Description:</b> Federal government program providing discounted phone or internet services to qualifying low-income consumers.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Details qualifications, ways to get Lifeline if qualified, and search for local services</li> </ul>
<p><b>Caption Call</b></p> <p><b>Website:</b> <a href="http://www.captioncall.com/">www.captioncall.com/</a></p> <p><b>Description:</b> Government-funded service providing free captioned phones for those with medically-recognized hearing loss.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• Captioned phone products available to order</li> <li>• Hearing health information</li> </ul>	<p><b>Supplemental Nutrition Assistance Program (SNAP)</b></p> <p><b>Website:</b> <a href="http://www.fns.usda.gov/">www.fns.usda.gov/</a></p> <p><b>Description:</b> Financial assistance to low-income families to buy nutritious food options.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• <a href="#">SNAP Application and Local Office Locators</a> to find a state application and office</li> </ul>
<p><b>Low-Income Home Energy Assistance Program (LIHEAP)</b></p> <p><b>Website:</b> <a href="http://www.acf.hhs.gov/ocs/programs/liheap">www.acf.hhs.gov/ocs/programs/liheap</a></p> <p><b>Description:</b> Helps low-income families heat and cool homes with weather upgrades or direct cash assistance for energy costs.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• <a href="#">LIHEAP State &amp; Territory Contact Listing</a></li> </ul>	<p><b>National Consumer Voice for Quality of Long-Term Care</b></p> <p><b>Website:</b> <a href="http://www.theconsumervoice.org/home">www.theconsumervoice.org/home</a></p> <p><b>Description:</b> Ombudsmen, or Citizen Advocacy Groups, advocate for and investigate resident complaints from nursing homes and assisted living facilities to ensure fair treatment.</p> <p><b>Key Resources:</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Locate an Ombudsman</a></li> </ul>

## GLOSSARY OF TERMINOLOGY

\* **NOTE: Definitions are based on the Centers for Medicare & Medicaid Services (CMS) Glossary:**  
<https://www.cms.gov/apps/glossary/default.asp?Letter=S&Language=English>

1. **Activities of Daily Living (ADL)\*** – Activities of daily living are basic tasks an individual does on a daily basis such as getting in and out of bed, dressing, bathing, eating and using the bathroom.
2. **Advance Directive (Healthcare)\*** – A document that discusses how medical decisions should be made in the event that a person loses their ability to make decisions for themselves. Advance Directives vary by each state’s law. To view your state’s Advance Directives, visit the National Hospice and Palliative Care Organization at: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>
3. **Assisted Living\*** – Residential facilities for senior citizens who live in their own apartment but are provided assistance for daily activities for an additional cost to the monthly rent charge. The range of services offered from facilities varies. To learn more about assisted living laws by state visit: <http://www.assistedliving.com/laws-by-state/>
4. **Caregiver\*** – An individual who provides paid or unpaid care to the elderly, disabled or ill by helping with instrumental daily activities such as eating, bathing, etc. Caregivers can be professionally licensed caregivers or can be relatives or friends.
5. **Dependent Tax Exemption\*** – A caregiver claims the care recipient as a dependent in their income tax return as long as they meet the criteria.
6. **Disability\*** – Physical or mental impairment that prevents an individual from fulfilling some or all of the daily living activities. In order to receive cash benefits through Social Security an individual must demonstrate proof of disability. Medicare is available for certain individuals with disabilities who are under the age of 65. However, they must have received Social Security Disability benefits for 24 months or have been diagnosed with End Stage Renal Disease (ESRD) or Lou Gehrig’s disease. There is also a 5 month waiting period between when an individual is determined to be disabled and the time they receive their Social Security Disability benefits.
7. **Disability Insurance (Old-Age, Survivors, and Disability Insurance-OASDI)\*** – Is a Social Security social insurance program that provides a monthly cash benefit for retired workers and their families as well as the survivors of deceased workers.
8. **Discharge Planning\*** – After an individual has been released from inpatient care such as a hospital, the process of deciding the types of care or services that the individual needs to go through is referred to as discharge planning.
9. **Dual Eligible\*** – Individuals who qualify for both Medicare Part A (hospital insurance) and Part B (medical insurance) and are also eligible for Medicaid. Full Medicaid benefits include coverage of full or partial co-payments, co-insurance and deductibles.
10. **Durable Power of Attorney\*** – A document that allows an individual to appoint a person to serve as an “agent” by enabling them to have authority to act on their behalf. There are two types of legal authority that an individual can designate to an agent: healthcare and finance. A power of attorney for healthcare gives the agent authority to make healthcare related decisions on an individual’s behalf. While a power of attorney for finance gives authority to the agent to make both legal and financial decisions on the individual’s behalf.
11. **Eldercare\*** – Consist of a wide-range of services and programs that include both public and private that are designed to help the elderly with housing, health insurance, long-term care among other services.
12. **Enrollment Period\*** – A set time frame in which an individual who is eligible for Medicare can enroll in a Medicare health plan.
13. **Family and Medical Leave Act (FMLA)\*** – Federal law that requires employers to provide employees with job-protected unpaid leave for medical or family reasons.
14. **Guardianship** – When an individual petitions to be a legal guardian for someone who is incapacitated due to age or disability. The individual petitioning the guardianship must go to the court and have the court declare that the person is incompetent to make their own decisions. The court then transfers the responsibility of managing finances, living arrangements, medical decisions, or other task to the petitioner.
15. **Healthcare Proxy\*** – An individual who has authority to make medical decisions for the care recipient.
16. **HIPAA (Health Insurance Portability and Accountability Act)\*** – A law passed in 1996 which guarantees patients’ rights and protections against the misuse or disclosure of their health records.

## GLOSSARY OF TERMINOLOGY (continued)

17. **HIPAA Privacy Waiver\*** – A legal document that allows an individual’s health information to be disclosed to an authorized third party.
18. **Home and Community-Based Services (HCBS)\*** – Provide Medicaid beneficiaries the opportunity to receive services in a community or their own home. It helps the elderly and disabled, developmentally disabled, and certain other disabled adults.
19. **Home Healthcare\*** – Healthcare services provided to an individual in their home due to an illness or injury. Services include intermittent skilled nursing care, home health aide services, physical therapy, occupational therapy, speech-language therapy, medical social services, durable medical equipment (such as wheelchairs, hospital beds, oxygen, and walkers), medical supplies etc.
20. **Hospice Care\*** – Hospice care is end-of-life care for terminally ill patients. The patient receives medical, psychological and spiritual support.
21. **In-Home Care Aide\*** – Provide care to individuals who are physically or mentally ill, injured, or disabled. The care is provided in the individuals own home or in a living residential care facilities.
22. **Last Will and Testament** – A legal document that discusses an individual’s final wishes in terms of their possessions and dependents.
23. **Living Wills\*** – A legal document that outlines the individuals wishes which include end-of-life care decisions or medical treatment options in certain circumstances.
24. **Living Trust** – A document that allows the individual or the person named as trustee, to transfer ownership or title of the assets into a trust.
25. **Medicaid** – A federal healthcare program that provides health coverage to low-income families, pregnant women, children, the elderly, and people with disabilities.
26. **Medicare\*** – A federal health insurance program for individuals age 65 or older or individuals under the age of 65 who have certain disabilities, permanent kidney failure, or amyotrophic lateral sclerosis (Lou Gehrig’s disease).
27. **Medicare Advantage Plan\*** – Health plan offered by private companies that have contracts with Medicare to provide individuals with Part A and Part B benefits.
28. **Medigap** – Medicare supplemental insurance that helps pay for health care cost that Medicare does not cover such as copayments, coinsurance, and deductibles, etc.
29. **Nursing Facility\*** – A facility that includes skilled nursing care and relate services for the rehabilitation of injured, disabled, or ill, or on a regular basis, health related care services.
30. **Nursing Home\*** – A residential location that provides individuals who can no longer live on their own, a room, meals, and help with activities of daily living and recreation.
31. **Open Enrollment Period\*** – A period in which you can enroll in a health insurance plan or make changes to their health coverage. During this period, they cannot be denied coverage or charged more due to past or present health problems. Open enrollment for the state health insurance Exchanges runs from November 1st to December 15th. Open enrollment for Medicare begins on October 15th and ends December 7th every year. Outside of the open enrollment period, an individual can only enroll in a health insurance plan if they qualify for special enrollment. An individual can qualify for special enrollment if they have certain life events such as getting married, having a baby, or loosing other health coverage.
31. **Out of Pocket Cost\*** – Healthcare costs that the patient must pay on your own because they are not covered by Medicare or other insurance.
32. **Personal Care Agreement** – An agreement between the care recipient and the caregiver that discusses the services and care that will be provided by the caregiver as well as any monetary compensation, if provided, that the caregiver will receive for those services.
33. **Power of Attorney\*** – A power of attorney gives you the authority to make financial decisions for someone else, such as signing checks to pay bills, handling tax returns, and selling a home. Unlike a general power of attorney, a durable power of attorney remains in place if the person for whom you are making decisions becomes incapacitated and cannot make decisions for himself or herself and it stays effective until that person dies or until they decide to revoke it.
34. **Skilled Nursing Facility\*** – A facility that provides inpatient skilled nursing care and related services to patients who require medical, nursing, or rehabilitative services.

## About Transamerica Institute®

Transamerica Institute® is a nonprofit, private foundation dedicated to identifying, researching and educating the public about retirement, health coverage, and other relevant financial issues facing Americans today. It comprises two research centers: Transamerica Center for Retirement Studies® (TCRS) and Transamerica Center for Health Studies® (TCRS). Its mission is to help educate and empower people to make informed decisions about important matters that can improve their health and wealth. Transamerica Institute (TI) is funded by contributions from Transamerica Life Insurance Company and its affiliates and may receive funds from unaffiliated third parties. TI and its representatives cannot give ERISA, tax, investment or legal advice. This material is provided for informational purposes only and should not be construed as ERISA, tax, investment or legal advice. Interested parties must consult and rely solely upon their own independent advisors regarding their particular situation and the concepts presented here. Although care has been taken in preparing this material and presenting it accurately, TI disclaims any express or implied warranty as to the accuracy of any material contained herein and any liability with respect to it.

## About the Inaugural Caregiver Survey and Caregiver Guide

This Caregiver Guide was derived from the research report, *The Many Faces of Caregivers: A Close-Up Look at Caregiving and Its Impacts*. The analysis contained in these materials was prepared internally by the research team at Transamerica Institute. The survey was conducted online in the U.S. by Harris Poll on behalf of Transamerica Institute between March 13 and April 21, 2017 among 3,074 caregivers. Respondents met the following criteria: U.S. residents, age 18 or older, and provided care for a relative or friend with an episodic, permanent, or temporary condition who needs help taking care of themselves (adult or child) at any time in the past 12 months. Results were weighted by race/ethnic groups [Hispanic, Black/African American (not Hispanic), Asian (not Hispanic), All Other (not Hispanic)] to each group's U.S. Census Bureau population distributions of adults age 18+ for gender, education, household income, household size, marital status, employment status; and to adjust for attitudinal and behavioral differences between those who are online versus those who are not, those who join online panels versus those who do not, and those who responded to this survey versus those who did not.

See [www.transamericainstitute.org](http://www.transamericainstitute.org) for the full report and additional materials.